

Lastly, he referred to the soft tissue and bone sarcoma regressions, saying that no explanation had yet been put forward to account for these although it might be that some were indeed embryonal tumours. He noted with interest that in the small collections of patients who had had a successful removal of a solitary metastasis in the lung a number had been from primary osteogenic sarcomas and testicular teratomas.

He stressed in conclusion that the study of the phenomenon of spontaneous regression in malignant disease was well worth pursuing because of the opportunity it provided for better understanding of the neoplastic process and the hope it supplied for better therapeutic control.

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### THE CARE OF THE TERMINAL STAGES OF CANCER

by

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“THE TERMINAL STAGES of cancer” may be defined as the time when all active treatment becomes increasingly irrelevant to the real needs of a particular patient. Many of the points I will mention are of course applicable to the time when palliative radiotherapy, chemotherapy and nerve block and section are used, but I am concerned now with the patient for whom these treatments are no longer helpful. It may be difficult to decide that this moment has arrived, but it is most important that we should recognize it and that we should remember that Sir Stanford Cade’s question, “What is the relative value of the various available methods of treatment in this particular patient?” (Cade, 1963), is just as pertinent now as at any other stage of a patient’s illness. We need also to be aware that this answer should frequently be decided in discussion by the whole group who have been concerned with the patient’s previous care.

Sadly, the terminal stage could also be defined as beginning at the moment when someone says, “There is nothing more to be done”, and then begins to withdraw, more or less subtly, from the patient. These people are very well aware when this happens. On admission to such a unit as that in which I have been working they make remarks that reveal this all too clearly. “It seemed so strange, no one seemed to want to look at me,” said one woman. The ward round had gone past the end of the bed, the three-month follow-up had been given when she knew her condition was changing week by week and finally the family doctor had sent the message about admission through a relative.

“To imply that nothing helpful can be done is inexcusable and seldom if ever true” (Smithers, 1960). Nor do we realize how much we can do simply by coming to see the patient when we feel that we have nothing to offer. We fail to understand what patients really expect of us. They

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are commonly too realistic to expect that we can take away the whole hard thing that is happening, but they do ask for concern and care for the distress and symptoms it is causing them. Above all, they ask for our awareness of them as people. At no time in the total care of a cancer patient is this of greater importance.

Hinton (1963) showed the high incidence of physical and mental distress occurring among patients dying in the wards of a teaching hospital, revealing how much we need to learn and to teach before we have the proper standards of relief for this stage, not only in special units but generally. We should aim for the relief that enables a patient to *live* until he dies as well as to die peacefully, that helps him to live as himself and not as what has been termed an "uncomplaining residue" (Weisman and Hackett, 1962). We need to be concerned with the quality of living, hard though it may be to judge such a matter for another person. At the same time, while we are not heedless of the possibility of regression, even at this stage, yet we have to see that this part of our care, even though it ends with the patient's death, is both positive and important in its own right.

It is the look on the faces of the patients that is the test of the efficacy of terminal care. Many students came to St. Joseph's Hospice for teaching rounds, often at their own request, for they are concerned at what is too often a gap in their education. They would arrive looking somewhat apprehensive, but in informal rounds were able to meet the patients alone and were shown by them the rewarding and positive nature of the work. For the same reason I lecture with slides and try to speak, not about "the terminal patient", but about Miss B. and Mr. A. "who happen to have terminal cancer".

Patients were referred to St. Joseph's by their treatment hospital when it had been decided that the time for active treatment was past. The majority came direct from their own homes at a stage when they had too much distress for home care to be possible any longer. They therefore had a considerably higher incidence of distress than would be found among a random selection of patients with terminal cancer; for example, among 1,100 patients in my own series more than 70 per cent had pain severe enough to need narcotics for its control. They often came after weeks or months of constant pain. They made such remarks as, "Pain? It was *all* pain", summing up in such phrases all the anxiety, the loneliness and the despair of long pain as well as the galaxy of physical symptoms common to this phase of illness. Although I will be concentrating now upon the approach of the doctor, this is not the whole story. It should frequently be the work of a whole team, a team in which the relatives are included.

Successful treatment should enable a patient not only to be free of pain but also to forget it and to concentrate on other things. If we are to over-

come the sense of failure that tends to pervade the atmosphere around the dying we need to be aware of the proper criterion of success in this situation. It is not to be seen primarily in our activities but rather in what the patient is achieving in the face of physical deterioration. This is as much a part of life as any other time and it may be the most important of all. The spirit often becomes stronger and more individual as the body becomes weaker.

The majority of patients and their families will choose home care if it is at all possible and they accept admission more easily if they have made the attempt. Here the caseworker will be needed, not only to arrange practical help but also to listen to and so ease some of the emotional tensions that arise or are exacerbated at this stage. On admission one sees in patients the signs of the anxiety of anticipated pain and in their families the feelings of guilt at having failed to continue the care of the patient. We cannot over-emphasize the importance of speedy relief and understanding at the moment of admission. A feeling of welcome and confidence can make the remaining weeks so much easier. Similarly, there are right and wrong ways of transferring a patient for terminal care. Not the sudden, unexplained omission from the round but the assurance that a full report is going to the new unit, not the unfortunate euphemism, "You are going for some convalescence", but the more truthful and eventually far less hurtful, "for longer term nursing than we can give in a busy general ward". Feelings of rejection so often burden these patients. One woman said to us on admission, "Will you turn me out if I cannot get better?"—using the word "cannot" rather than "do not". The feelings of guilt that are so much a part of cancer are often imposed upon these patients by others.

I have little time to discuss the problems of the families but for them too the moment of admission is of great importance. They need our reassurance if their inability to carry on any longer at home is not to give rise to bitter feelings of guilt, and they need to talk through their fears just as much as the patient does. Some are inarticulate, and most need more than one interview, but all will be helped by seeing the patient look comfortable, relaxed and relieved, better and happier for entering hospital. Indeed, we may see that the family has more chance to meet now than they had during the hours of distress at home. This in itself may help immensely towards relieving some of the distress of bereavement. Much of this is the work of the ward sister or the social worker, but having worked in all three roles I know that there are demands that should rightly be met by the doctor and that the care of the family comes within his sphere of responsibility.

The perennial question, "What to tell the patient?", is central to all the problems of management. The problems of giving a diagnosis of cancer or of warning of a poor prognosis are two very different things, although not necessarily so in the mind of the patient or his family. But

at the stage we are discussing it is far more often the latter that they wish to discuss and we rarely use the word "cancer". Occasionally a patient will introduce it, and when they do, or when we have reason to suspect that it is in their minds, we should quickly reassure their almost inevitable fears of uncontrollable pain, either directly or indirectly.

Patients watch us as we watch them. They want to see what we are thinking and they will wait until they believe that we will listen to what they have to say. I recall a young woman who, after two months with us, suddenly asked me, "Doctor, where did all this begin?" and then, once she was certain of my attention, "What I *really* wanted to ask you was—is it wrong for me to let my children come up and visit me, now that I am getting so thin?" She well knew both her diagnosis and her prognosis for she had learnt them by listening to the round at the end of her bed after a laparotomy some six months earlier, but now she had other questions.

She could not ask them of her husband, for she had not been able to talk with him either. But once she had talked with another person, that barrier disappeared, and they spent her last ten days talking through their plans and their parting. Her quiet acceptance and peace held the whole family in the calm that shows in a photograph taken one week before she died. She waited until she had questions to which she needed an answer. Others do the same, and their questions are likely to be something about their families, about the possibility of pain, hopes of a quiet death in sleep or, simply, "What will it be like at the end?" It is sometimes said that patients do not want to ask questions of this nature. They do not ask when they know that they will not get any answers or merely the barrage of reassurance that is aimed more at the feelings of the doctor than at those of the patient. The support needed by these patients is often given as well or better without words and must always be in our own fashion. There are two parties to these discussions. Talk about symptoms can be a way out of disturbing discussions but it can also be a way of giving encouragement at a deeper level. Above all, we need to have confidence in the courage and common sense of our patients and to wait for the clues they will give us if they know that we are ready to pick them up. If we can never bring ourselves to talk with them of these matters perhaps there are others who both could and should be doing so instead.

One half of our 1,100 patients openly discussed with us that they realized that they were not getting better. Many of the rest were not capable of realizing this or of discussing it had they done so. We believe that most alert patients reach insight even when they do not ask and are not told. Hinton (1963) found that 50 per cent of his group of 102 patients had a shrewd idea of how ill they were when he first met them and that three-quarters came to realize it before they died. He did not tell them and they were not told any more frequently than patients commonly are in hospital, and the staff of the wards frequently did not know that they had this knowledge before Hinton gave them the unhurried

opportunity to talk. Patients do not only rely upon the information given to them by their doctor—there are many other ways of acquiring insight—the processes of disease, past experiences with other people, the silences, evasions and denials of others. As one patient of ours told us, “When the hospital said nothing—and my doctor said nothing—then I knew.” Discussions on this subject commonly tell us more about the doctor’s attitude than the patient’s.

The important question should be phrased: “What do you let your patients tell you?” Not every patient wants or needs the whole truth, but everything that he *is* told should be true, even if it is expressed in the most gentle way possible. Once he finds that he has deliberately been deceived he feels totally deserted—alone with the truth that others have persuaded themselves they have hidden from him. The best communication is often indirect and we all know that deep understanding which never needs to be expressed in words at all.

The family are commonly more frightened of the truth than is the patient. A man whose family were desperately anxious that he should never be told remarked calmly to me one day, “Of course, it isn’t a question of cure now is it, it’s just jogging along.” Fear fades away and death is not frightening once it is near. We need to help the families to try and keep in step with the patient’s own progress, so often towards a peaceful acceptance of the situation. Not infrequently he is the one who is best able to handle it. I remember one man saying to us, “I’ve had it all out with my wife. Now we can relax and talk about something else.”

We must not forget the human capacity to hold two incompatible truths at the same time, to talk about one at one moment and the other the next, to make unrealistic plans or in other ways to relax the tension. A patient does not always wish to be concerned with solemn matters and we have to keep in touch with his constantly changing needs. We also have to recognize those who deny the reality of what is happening or who never wish to have it confirmed in words.

The dying are very courteous, they will rarely ask us questions that we are not able to answer. They often know us better than we know them. But when we do know them, there is infinite variety and infinite interest to be found in the ways in which they come to terms with the situations of terminal illness. They should be kept in the centre and should be involved in the making of plans, in the care of the children of the family, and, as far as possible, in the life they have always led. The full life with all its satisfactions is easier to leave than the empty one, and the dying need to know that they are needed, that they can still give something and that they still belong. It is hard for them as well as for their families if they are never able to say goodbye.

The problem of pain has already been discussed to-day but there are special points in its management at this stage. Terminal pain can fill

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the whole consciousness of a patient and be a most complex and interwoven problem. A patient described it: "All of me is wrong". She did not mean merely her many related symptoms but also her feelings of isolation, the family's social problems connected with her illness and her need for a sense of meaning and security. Our treatment should be based on an equally wide approach.

If we are to relieve such pain while the patient remains alert, never rendered stuporose by drugs, we need to make a careful analysis of its components and treat each symptom specifically. The doctor who gives attention to detail and who has various ways of dealing with dyspnoea, anorexia and nausea, bowel disturbances and all the other common problems, will go to his patient feeling positive and will transmit this attitude. Each gathers a list of his favourite remedies and an excellent source is to be found in the suggestions of experienced ward sisters. Here is the place where symptomatic treatment is mandatory and for the modern equivalent of the elegant prescriptions of a former generation of physicians. We are now dealing with a generalized disease, probably involving more than one system and with a multiple symptomatology, and there is no longer any definitive treatment to offer.

Pain and the relief of pain are self-perpetuating. At this stage it is extremely important that we should anticipate a patient's pain so that he does not do so himself. Chronic pain is fundamentally different in its impact from post-operative or other acute pain. Patients with the constant pain that is so typical of terminal cancer need their analgesics given regularly rather than on demand, used to prevent pain from occurring rather than to control it once it is present, already exacerbated by fear and tension. Drugs should be related to need so that they will control pain for a period slightly longer than the chosen routine time. They should be given to a rather relaxed time-schedule so that no one is obsessively clock-watching. If patients have to ask continually for analgesics they are reminded each time of their dependence upon them and upon the person who gives them. As their physical dependence increases we should aim to give them all the independence we can in other spheres.

Those who work constantly with these patients find that narcotics are still the drugs of choice for the relief of severe terminal pain and that if their use is properly managed they will maintain their usefulness over long periods. We found that on a regime such as the above, coupled with constant use of adjuvants and symptomatic treatment (*Drug and Therapeutics Bulletin*, 1965; Saunders, 1964), most patients could be relieved of pain by comparatively small doses and that the great majority needed little increase in dose. In one series of 200 patients 49 were with us for more than three months, most of them having diamorphine throughout that period. Two-thirds of all their doses were given orally and only nine patients ever needed more than the standard 10 mgm. dose.

Tolerance and drug dependence is too often due to faulty management. Physiological dependence is not a matter of great concern at this stage, but emotional dependence is an intolerable burden to the patient and all around him, even if it only lasts for a few days. We need more research into the control of chronic pain if we are to give rational teaching about this subject and ensure that these patients, wherever they may be, are neither swamped by distress nor smothered by treatment or the miseries of dependence. They also need more than our skill. They need the enthusiasm which recognizes and encourages the achievements in dying that are proper to the individual and will yet detect the signs of the very occasional remission that may occur even at this stage. When we have seen the relief of distress lead into such remission we have not found it difficult to withdraw diamorphine (our own well-tried drug of choice), or any other analgesic.

Those who have known these patients will have seen how often mental distress is linked with their physical problems. The fear so commonly caused by dyspnoea, the depression that accompanies anorexia and nausea and the feelings of guilt aroused by incontinence are all eased by treatment of the physical cause. We may need all our ingenuity and persistence to do this successfully, but often the greatest help we can give is our understanding and the reassurance that many of their feelings are physical in origin.

There is little time to discuss the drugs which have so transformed the treatment of terminal distress over the past few years. Strong analgesics should generally be used in combination with adjuvants, particularly the drugs of the phenothiazine group, but we have to balance the dose carefully to the individual patient's need and personality lest we over-sedate him. These drugs should be used to anticipate distress. If we recognize the first signs of confusion (often incipient paranoia), we can usually avert a crisis.

Alcohol has an important place in treatment. It is often the best sedative for the elderly and should also be employed for the opportunities it gives for social exchange. Man is a social being and will still find gratification in being convivial or in a relaxed moment with family or friends. I remember telephoning the family doctor of a patient who had been discharged from our wards and who had had several good months at home before his death. I asked the doctor whether he had increased the diamorphine while the patient was at home. "Very little," he replied, "but we pushed the whisky up a fair bit."

Nothing that we give releases us from the demands upon our own interest and concern. Profound loneliness may seem to make a patient quite inaccessible. The temptation may be to give over-heavy sedation, yet he will be surprisingly accessible to a personal approach and needs a listener more than any drugs. Each will enhance the effect of the other. The

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short visit which can be relied on is often of more value than the infrequent longer call. Above all, these patients must never be passed by—they are deeply wounded by being omitted from a round. The less one can do the more one should be certain that they are never left out. The grumbles of the strong personality who not surprisingly finds dependence hard after a life of determined activity and the unexpressed fears that can be so threatening will often evaporate if they can be voiced. Unrelieved, both can herald confusion. Depression can go sadly unrecognized in a busy ward and responds better to the relief of a narcotic-cocaine mixture than to the anti-depressive drugs. It is lifted by physical relief and, again, by the listener. Those who meet these patients are constantly impressed by their admirable courage and realism and sometimes by the unquenchable individuality which can greatly add to the humour of a ward if not always to its calm.

Death from cancer in hospital is not always as peaceful as it should be; we need to discern the time when the proper treatment of a haemorrhage is morphine alone and when a tracheotomy should not be performed. Dehydration will often respond to the unhurried favourite drink and the family may then be able to help instead of having their distress increased by feeling useless and in the way. A multiplicity of tubes may give no help and only detract from the proper dignity of dying.

It was my great good fortune to work with such a staff as that of St. Joseph's Hospice, but the atmosphere of its wards came as much from the patients as from the nuns and their nurses. It came from the maturity we saw so often and from what can only be described as the gaiety of those who have come through doubts and fears and on into an active acceptance. We will never stop trying to help these patients, but we have to be sure that what we are doing is both relevant and helpful to them. We watch them move from the fight to live into the acceptance of dying—a positive attitude quite different from an apathetic resignation. If we fail to go near them we may never see this. If we do, it can change our whole attitude to this situation and to the people in it. Here we have reached the borderline between the practice of medicine and its philosophy and, perhaps, this is the best place for us to consider such things. What we will learn here comes through the patients themselves. When we look back we remember not what death has done to them but what they have done to our thoughts about it.

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